



Community Youth Work Practice and Autism Spectrum Conditions

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Community Youth Work Practice and Autism Spectrum Conditions **Understanding, Inclusion and Participation**



January 2019

Community Youth Work @ Magee
School of Applied Social and Policy Sciences

Conference Convenor - **Dr. Breda Friel**
Conference Report - **Clare Harvey**

***Inclusion is
belonging,
inclusion
begins with
you***

Dylan Clarke,
SONAS Youth Club

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INTRODUCTION AND RATIONALE

Autism Spectrum Conditions (ASC) affect the way a person relates and communicates and according to the NHS Information Centre are estimated to affect around 1% of the UK population. That's 700,000 people who live with the condition which affects the way they process, experience and socialise within society.

Community Youth Work (CYW), as a discipline, aims to be responsive to emerging trends in practice across the sector. The past number of years has witnessed the development of knowledge, interest and understanding of the needs of young people with Autism Spectrum Conditions and provision in this area of Community Youth Work practice is continuing to expand and develop.

Such developments have witnessed increased numbers of students and practitioners developing programmes and carrying out research on the experiences of young people with ASC aimed at improving participation and inclusion. Emerging themes in Community Youth Work include improving training and provision, understanding and assessing needs and addressing issues affecting those with ASC, such as mental health, isolation, and emotional well-being. As a consequence of these developments across the Community Youth work sector and to facilitate sharing best practice in the area of ASC the **Community Youth Work Practice and Autism Spectrum Conditions - Understanding, Inclusion and Participation** conference was held on January 25th 2019 at the Magee campus.

Conference organiser **Dr Breda Friel** said:

"The key aim of the conference was to provide information, tools, and strategies to support young people with Autism Spectrum Conditions across the community youth work sector. We do our best to highlight the voices of people with ASC and in partnership with YWelp Erasmus colleagues from Melbourne, Finland, Estonia and Maynooth and supported by Youthpact Peace4Youth, we welcomed 160 delegates who attended a very successful conference."



WELCOME

The conference was opened by Philip Mc Dermott, Senior Lecturer, Sociology, and Susannah McCall, Associate Head of School, Applied Social and Policy Sciences. Both extended a warm welcome to Magee and highlighted the college's proactivity in engaging with the community, collaborative working, and production of innovative research.

The background to the event was discussed, including the YWELP (Youth Work e-Learning Partnership) international project funded by Erasmus+, which has a focus on digital approaches to youth work, diversity and human rights. The conference aim, to deepen our knowledge of autism spectrum conditions, to reflect on best community youth work practice, develop new partnerships, and to influence outcomes for both policy and practice was outlined.

Participants were encouraged to learn from those with experience of practice with ASC, to develop networking and new partnerships, to share ideas and expertise, and also to hear from the global perspective of conference contributors from Australia, Estonia and Finland.



KEYNOTE SPEAKERS

Jane Hickey, Victoria University, Melbourne

Considering autism using a strengths-based approach

Jane began by reflecting on how perspectives about autism have shifted over the last century. She recounted an early view of autism as the childhood onset of schizophrenia, or the belief that mothers who displayed a lack of empathy – historically referred to as ‘refrigerated mothers’ - were to blame for their child’s condition. These early clinical understandings of autism as a collection of deficits are indicative of the medical model which locates disability as a problem within the individual, and hence places emphasis on diagnosis and on treating or curing the individual.

A later perspective depicted autism as a linear spectrum, which Jane compared to a vertical length of string with high functioning at the top and low functioning at the bottom. Those perceived as at the bottom of the string were assigned lower social value because they were less likely to contribute economically within society. The focus of this linear view of autism was on how to move people ‘up the line’ and to increase their functioning. As with the medical model, this ontological view of autism depicts a limited and static understanding of autism and leads to a focus on fixing individuals in order for them to ‘fit’ within society.

Jane then outlined the significant influence of disability activists -including Tom Shakespeare et al -who introduced a social model of disability in the 1980s. This model identifies disability as a social construct and states that people with impairments are faced with disabling barriers created by an environment which excludes them. This shift from the medical to the social model has had a profound impact on interventions. The focus within the social model is on society, ie. how do we create a community which enables people with impairments rather than excluding them? The social model is a strengths-based approach which considers ‘disability’ as the result of the interaction between those living with impairment and an environment.

Turning to the current understanding of autism, Jane rejected the notion of a linear and static spectrum and proposed that a sphere of inter-related elements is a more helpful representation. The dimensions of the sphere indicate how autism is complex and diverse, rather than static. She highlighted Jacqueline Den Houting’s view of neurodiversity, which says that the autistic brain is neurologically different and so autism should be accepted as a “way of being” – as a diversity rather than a deficit.

Jane explained how the strengths-based approach considers people with autism spectrum conditions as whole people. In particular she referenced the work of Wayne McCashen, who has developed a framework of practice which says that everyone in the community has strengths to contribute to the whole. This perspective places a value in everyone, it rejects labelling, and states that everybody has an ability to flourish.





A video entitled Joshua's story was shown, in which Joshua described his experience of being misdiagnosed until his late 20s. He challenged some of the common myths, for example the view that autistic people do not have empathy for others. He urged youth workers and educators to do their research about autism, to listen to individuals and to understand that they may have specialist interests and 'esoteric knowledge'.

In concluding, Jane highlighted a statement by Miller and Katz (2002) that 'Inclusion is a sense of belonging, feeling respected, valued for who you are, feeling a level of supportive energy and commitment from others so you can do your best work'.

She proposed four recommendations:

- More research is needed to support young women with autism, as there are disproportionately fewer females being diagnosed than males
- In Australia there are challenges in diagnosis and the need for a national approach to diagnosis – this situation may be familiar to Northern Ireland
- The media should accurately depict the lived experiences of autism
- We should consider disability inclusion more broadly, acknowledging the social model of disability and the rights-based requirements to involve and accommodate people with disability in all aspects of community life.

1 Considering Autism: using a strengths based approach

Jane Hickey
Victoria University, Melbourne Australia
Derry, Northern Ireland
25/01/2019

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OVERVIEW



TIMES GONE PAST

- Understanding of disability has changed over time

WHAT'S HAPPENING NOW

- Autism as a expression of divergence, rather than deficit

JOSHUA'S STORY

- The lived experience "Nothing about us, without us"

INTO THE FUTURE

- Using strengths based practices to work with young people with Autism

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3 The Past

- The Autism definition, causes and diagnosis have changed over time.
- "Childhood schizophrenia" and "refrigerated mothers" of the early 1910s-1950s (Zaky 2017)
- Clinical understanding of disability was that there was a 'problem' within the individual that needed to be fixed, treated or cured.



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4 The Medical Model of Disability

- The **medical model** of disability considers a 'disability as a "problem" that belongs to the disabled individual. It is not seen as an issue to concern anyone other than the individual affected. For example, if a wheelchair using student is unable to get into a building because of some steps, the medical model would suggest that this is because of the wheelchair, rather than the steps.'

• (University of Leicester 2015)

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5 Understanding that changes overtime.

- When I began working with young people 20 years ago in Melbourne, this is the way that I was taught about Autism.

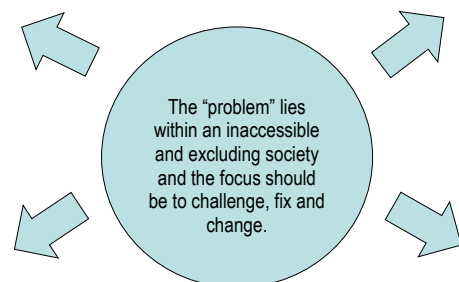
- A piece of string



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6 The social model of Disability

Disability activists such as Mike Oliver (2013) and Tom Shakespeare (2018) challenged the medical model of disability.



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7 Social model of Disability

- The **social model** is a strengths-based approach that considers: 'disability' is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others.'

• (People with a Disability Australia, 2015)

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8 The Present



- Sphere of interrelated elements- growth mindset
- Not a linear spectrum of functioning, but rather a complex interrelated elements
- Autism as neurodiversity: views Autism as diverse and a way of 'being', rather than a deficit (Den Houting 2018)
- Strengths based approach (McCashen 2010)

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Inclusion: what does it mean?

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- Inclusion is a sense of belonging: feeling respected, valued for who you are; feeling a level of supportive energy and commitment from others so than you can do your best work.

(Miller & Katz 2002)



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The Future- what do we want the future to look like?

10

- More research to support young women with Autism as there are still lower numbers of young women being diagnosed than young men- why?
- In Australia, there are challenges in diagnosis and calls for a national approach to diagnosis
- Media to accurately depict the lived experience of Autism.
- More specifically, we 'should consider disability inclusion more broadly, acknowledging the social model of disability and the rights-based requirement to involve and accommodate people with disability in all aspects of community life.'

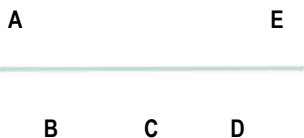
(Australian Local Government Association 2016, p 9)



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Where does the letter 'F' belong? Above the line, below the line?

11



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CONTACT DETAILS

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Dr. Breda Friel, Ulster University, Magee

Overwhelmed: Living in an intense world



Breda noted that her presentation draws not only on her community youth work background but also on a therapeutic perspective based on experience of practice in the area of mental health and critical incident management and debriefing.

Posing the question, what is life like for young adults when they find themselves overwhelmed and living in an intense world, she observed that young people with autism spectrum conditions -and particularly young women - may develop coping strategies which lead to exhaustion, anxiety, and even selective mutism. Worryingly, statistics show that young people with Aspergers have a higher risk of suicide in comparison to other clinical groups. Young people who feel overwhelmed believe that 'being me' is not enough, they may feel incongruent and that they 'don't fit'. These young people face emotional damage when trying to negotiate a neurotypical world, in which there is a misfit in how the social world interacts with them. Issues of social context and understanding of social roles can lead people with an autism spectrum condition to struggle in many ways, which can manifest in depression, loneliness, fear, social isolation, underachievement and unemployment.

Breda strongly challenged the deficit approach to mental health and highlighted the benefits of positive psychology and the strengths-based approach. She noted the need to challenge the terminology surrounding the concept of 'normal', and to modify our understanding of aspects of autism spectrum conditions. For example, when talking about repetitive behaviour, we should appreciate that this can be a learning approach by young people rather than a problem behaviour.

Breda noted that young people at the high functioning level can mask their difficulties very well and therefore go under the radar, experiencing years of isolation, bullying, feeling different and overwhelmed in the environment. Practitioners within education and social and youth work should be cognisant that crisis points can occur particularly at times of transition such as school change and employment.

Breda reflected on how the 'gifted' are often very misunderstood and may be perceived as excessive, troublesome and over-excited. Persistent curiosity may be misconstrued as aggression, the tendency to question may be considered as undermining, traits of deep sensitivity may be misinterpreted as immaturity, self-directness may be seen as oppositional.

This leads us to reflect on what is 'normal', and the need to recognise that the statistical norm or average is an inappropriate measure within the life sciences. She contended that a more appropriate focus is on what is 'optimal' or well-developed, rather than what is normal or average.

Regardless of our professional discipline, Breda stressed that we need to realise the experience of intensity felt by high-functioning young people with autism spectrum conditions. They experience intensified pain, overstimulation and conflict. Breda referred to the theories of Kazimierz Dabrowski (1902-80) and his study of gifted people and their emotional extremes (which he referred to as 'over-excitabilities').

Breda noted that within the clinical practice she sees young people who are very critical and negative about themselves, who feel frustrated and inferior, who feel they are at fault and believe themselves to be social failures. The question is, how do we support them? In this context, the work of Dabrowski offers a constructive approach. His theory of positive disintegration states that 'inner fragmentation' is actually part of human development for the gifted individual. Applying this theory to practice, Breda contended that the supportive response in a therapeutic setting should encompass:

1. **Confirmation that I am not flawed**
2. **Affirmation of self as you are**
3. **Work to the individual's capacity**
4. **Managing self and emotion.**

In relation to autism spectrum conditions, Breda reflected that there are still issues of misdiagnosis and also missed diagnosis. She concluded that:

- **We must challenge the deficit approach, the myth of 'the normal', the average, in our understanding of inclusion and participation**
- **Our practice must go beyond traditional approaches to strive for opportunities that aim towards optimal well-being**
- **Training towards self – in appreciation of excellence and allowing the self to be**



Slide 1

Overwhelmed: living in an intense world

Dr Breda Friel SFHEA,
Lecturer in Community Youth Work

Slide 2

Presenter

- 1996 – Ulster University
- Social work – Probation – Community Youth
- MIACP, MBACP & PTSD Specialist
- Counsellor Therapist
- PhD – Relationship between the Community, Voluntary and Statutory Sectors on the Process of Developing Suicide Prevention Policy in Ireland



Slide 3

Examples - Civic Engagement in the North-West- Responding



Slide 4

Jeannie Davide-Rivera, *Twirling Naked in the Streets and No One Noticed: Growing Up With Undiagnosed Autism*

- *"My colors ran all over the page, poured out of the lines and meshed together to form colors no one had yet recognized. I was different—unique, bold, strong, smart, and hard-headed. I was simply me."*
- Context of this presentation
 - Therapeutic practice
 - CYW –changing practice
 - Challenging assumptions

Slide 5

Liane Holliday Willey,
Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life

- Females with ASDs often develop 'coping mechanisms' that can cover up the intrinsic difficulties they experience. They may mimic their peers, watch from the sidelines, use their intellect to figure out the best ways to remain undetected, and they will study, practice, and learn appropriate approaches to social situations. Sounds easy enough, but in fact these strategies take a lot of work and can more often than not lead to exhaustion, withdrawal, anxiety, selective mutism, and depression. -Dr. Shana Nichols"
- Male/female

Slide 6



Settling and turning

- Senses
- Boundary
- Turning toward self
- Incongruence
- Experience
- When being me is not enough

Slide 7

Review and revision

- Language and terminology -Challenge
- Strengths based approaches
- Communication
- Social Interaction - engagement
- Restricted – distinct and unique Interests
- Repetitive Behaviours - learning style and a coping strategy
- Normal!
- Revise...



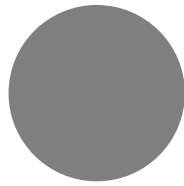
Slide 8

Hodge and
Rutten
(2017)

- Focus on AS
- Focus on Intensity
- Experiencing difficult environments/practices- emotional damage
- Negotiating neurotypical social world
- Asperger misfit between modes of being and social world (Rutter:2005)
- Differ: Asperger (AS) wishes for social communication yet struggles with social processes to achieve it
- HFA more often considered less concerned about emotional/social isolation

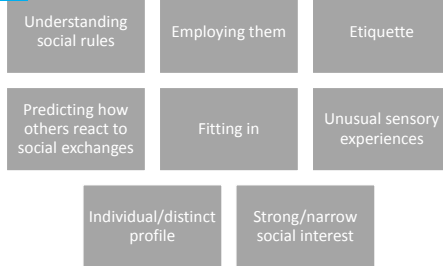
Slide 9

- Condition within spectrum – mode of communication/social engagement – profound difficulties
- Modes of being – misfit between physiology and the environment NOT developmental experience (Rutter:2005)
- Social communication
- Social interaction
- Flexibility of thinking (Wing:1996)
- Problematic understanding self and non-autistic ways of being



Asperger

Slide 10



Social context

Slide 11

Mental health

- Irish Autism Association
- UK research (N=377)
- 9 times more likely that peers to have suicidal ideation
- 66% had thought and 35% Planned
- Our findings confirm anecdotal reports that adults with Asperger Syndrome have a significantly higher risk of suicide in comparison to other clinical groups, and that depression is a key risk factor in this," commented lead researcher,
- Dr Sarah Cassidy, of Cambridge University's Autism Research Centre
- Gill, L. (2016)



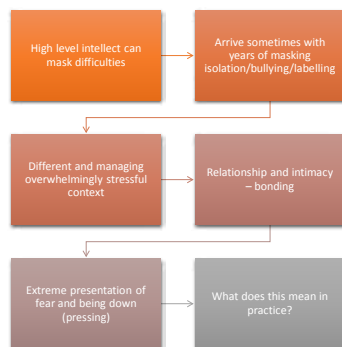
Slide 12

Struggle

- Depression
- Loneliness
- Social isolation
- Exclusion
- Under-achievement
- Unemployment
- Lack of community services
- Vulnerable – Easily influenced – social cues
- Offending – victim
- (Gill:2016)

Slide 13

The therapy space



Slide 14

Intensity and giftedness

- Emotional intensity
- Stimulated by what's around and what moves from within
- Misunderstood
- Excited v excessive
- Persistent v nagging
- Questioning v undermining
- Emotion and sensitivity v immaturity
- Self-directedness v oppositional

Slide 15

What is normal

- Outside the normal
- Exceptional
- Viewed as abnormal
- Annoying or bad ...
- Statistics-average constitutes norm (wage, intelligence)
- Convention
- Statistical norm is a poor guide to what is good

Slide 16

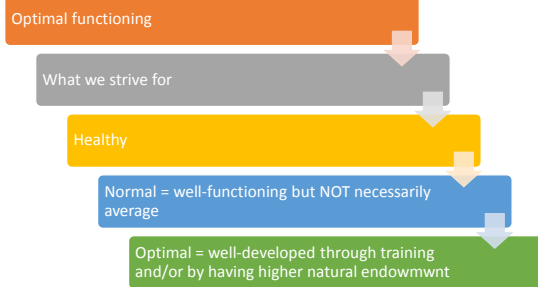
psychology

- Origins
- Models in physic/natural sciences
- Not based on life sciences
- Normal NOT average RATHER what is well-functioning



Slide 17

optimal



Slide 18

Community Youth Work

- Distinction between:
- Helping
- Therapeutic
- Youth work

Slide 19

Challenge for youth work

- Participation
- Inclusion
- Challenge
- Awareness
- Understanding

Slide 20

Barriers

- Invisible
- Labelled "weird" odd
- Marginalisation
- Lack understanding
- Want to belong – encounter rejection
- Hard to reflect
- Emotions/feelings don't make sense
- Facial gestures not typical
- Reading non-verbal hard
- Bullying

Slide 21

What works

- Fear of revealing
- Practical processes difficult
- Acceptance
- Environment
- Relationship
- Address what they are concerned with
- Task over process in group/individual work
- Idiosyncratic

Slide 22

Attwood (2004)

- Explicit
- Clear guidelines and instructions
- Useful-practical-accessible
- Abstract present as visual concrete
- Written
- Processes over time
- Rehearsal
- Social skills training
- Practical strategies for managing communication
- Spontaneous can be hard

Slide 23

support

- Subjective experience – understood
- Empathy
- Reflection and capacity
- Improving the environmental factors to reduce isolation
- Role of youth work
- Centre based work
- Programme planning
- Pets and animal work example
- Social support package – buddy system

Slide 24

Less typical

- Modes of thinking
- Feeling
- Experiencing
- Engagement
- Challenging
- Present the self differently
- Enrich

Slide 25

Coyle (2011)

- ASD training and
- Intervention
- Training in education
- Review of Provision
- Resources and support
- One to one relationships – integration
- Family partnership working
- Guidelines and frameworks
- Participation

Slide 26

conclusion

- The capacity to identify, learn appreciate and understand different ways of being in the world is the essential necessity for effective youth work and interventions with people with AS

Q&A

Breda & Jane invited questions from the floor.

Q: Can you elaborate on the idea of masking – if young people don't mask themselves then they may come into conflict with their peers?

A: This issue highlights the need for a multi-disciplinary approach to support young people

Jane noted that masking begins from early childhood and so children need to understand difference and diversity from a young age. She welcomed the fact that Sesame Street now features an autistic character. In the school system our approach should be to increase the status of the autistic child within the classroom.

Q: Is there a potential to use creative methodologies in our work with autistic young people?

A: Yes, certainly. There has been a recent focus on technical activities such as IT clubs and technology industries because the technical part of the autistic brain is often developed. However the social and expressive aspects of the arts, e.g. drama would be very beneficial.

Q: How do we respond when some cultures dismiss that autism exists?

A: Agree that many families have different understandings of autism, and in some families there may be a shunning or shaming of the child. The strengths-based approach needs to be applied with the entire family – however we need a lot of sensitivity when challenging familial and cultural perspectives, and we also need to ensure enough time to build relationships with the family.

Q: What is the scope for non-verbal autists within the strengths-based approach?

A: Using the social model we accept that the communication barrier lies within society, we believe everyone can communicate given the resources, and so we need to make sure all materials are accessible. Society must adapt to enable alternative methods of communication with its non-verbal citizens.

Q: Can oppositional behaviour be turned from a negative into a positive?

A: This refers to boundaries and how we react to oppositional behaviour – the issue brings into question the impact we have on each other

We should also be mindful of the onset of adolescence – taking autism out of the equation, adolescents shift towards their peer group and diverge from parents, it can be an oppositional stage of life. Young adolescents with autism may face additional challenges.

KEYNOTE SPEAKERS

Liam Gill, Dylan Clarke, Darragh Fullerton, SONAS Youth Club

Promoting positive outcomes with individuals with autism spectrum conditions

In 2006 iCare (Inishowen Children's Autism Related Education) opened a centre in Donegal, and six years later it developed the SONAS youth club. Currently SONAS has 51 members and provides youth work activities and support for individuals with autism, their families, and professionals.

Liam briefly described the very different characteristics and interests of three individuals who attend SONAS, and the variation between them illustrates the width of the spectrum and diversity of young people with autism. However they share the same core aspirations with any young person, namely to be happy, healthy, have good mental health and enjoy a sense of autonomy. SONAS provides support to young people to achieve these aspirations by creating a supportive environment, using positive reinforcements, realistic goals, schedules and structure and negotiated care plans. The club workers are mindful of the environmental barriers which may trigger behaviours (such as lighting, high-pitched sounds, open doors etc).

In terms of enabling young people's right to participate, SONAS follows a model of participation developed by Laura Lundy from Queens University Belfast. This comprises four elements:

- **Space** - young people must have safe opportunities to express themselves
- **Voice** - they must be facilitated to express their views
- **Audience** - they must be listened to
- **Influence** - their views must be acted upon, as appropriate

A video was shown which illustrated the range of activities within the SONAS youth work programme, including the two-year Leadership for Life course. SONAS facilities include a gym, computer suite, cookery room and softball area. In addition to the youth work programme SONAS has developed partnerships with other community and voluntary groups, and with local schools and colleges.

Liam noted the parallels with mainstream youth work. Practice within SONAS is underpinned by core youth work values, the process is valued as well as the product, and there is a central concern with young people's personal and social development. The outcomes for young people who attend SONAS include making friends, greater communication skills, social skills, involvement in planning, confidence, life skills, qualifications, prevention of rural isolation, promotion of happiness, health and well-being, positive stimulation, improvement of verbal ability and increased resilience.

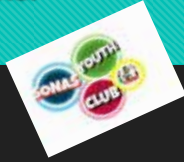
A video was shown depicting the experience of a SONAS member Dylan Clark, and this was followed by a presentation from Dylan. He described his childhood, his late diagnosis, his passions and his difficulties. He has been a member of SONAS for seven years and graduated from their Leadership for Life programme in 2018. He spoke movingly about the positive impact which participation has had 'SONAS has helped me to see things differently but allows me to be myself'. SONAS has been a key feature of his social life, a space where he has made friends and has developed a support network. 'For me, inclusion is about belonging. Inclusion begins with you'

Another member of SONAS, Darragh Fullerton, gave a concluding presentation. Darragh talked about his experience of SONAS which he declared had been life changing. Having been a member of SONAS for the past six years, he spoke passionately about the importance of friendships, of feeling included, and having shared interests and common experiences. Like Dylan, he had completed the Leadership course, and he found that the self-reflection aspect of this course helped him to appreciate 'who I am and what I can do'.



1 Promoting positive outcomes through youth work with Individuals with Autism Spectrum Conditions.

By Liam Gill, Sonas Youth Club



2 i.C.A.R.E.

- Inishowen Children's Autism Related Education Limited was founded in September 2000 by a small group of parents of children with Autism. They came together in response to the huge need for local support, training and information.
- In 2006 iCARE opened a centre for individuals with autism and their families to provide respite, support, education and informal learning.

3 Sonas Youth Club

- In October 2012 through iCARE and a course I was studying at Ulster University, I established Sonas Youth Club. The key aim of the youth club is to provide informal education, youth work, and support for individuals with autism, their families and professionals involved in the area of autism.

- Example of 3 young people who attend Sonas Youth Club



5 Developing a more inclusive youth work practice.

- Create an environment of Inclusion
- Use positive reinforcement
- Modify goals
- Review the activity
- Gauge their interests/hobbies
- Keep goals realistic
- Provide live demonstrations
- Schedules and structure helps
- A care plan devised with parents or guardians
- Flickering lights, high pitch sounds, opened windows or doors could trigger behaviour.

Happiness & Wellbeing:
The majority of us want to be:



HAPPY



HEALTHY



HAVE GOOD
MENTAL HEALTH



IN CHARGE OF
OUR OWN LIFE

7 The Lundy Model of Participation



Space



Voice



Audience



Influence

8 Programmes

Leadership
for Life

Drugs &
Alcohol

Exploring
Mental
Health

Social Skills

Road Safety
Awareness

Employment
Skills

Independent
Living Skills

Relationships

Creativity

Health &
Wellbeing

Personal & Social
development

Informal
Learning

Cyber
safety

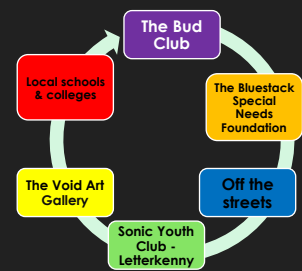
Video

9

<https://www.youtube.com/watch?v=VSYNNPLXNl0>

Here are some organisations we have linked with:

10



Successful Outcomes:

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- The young people planned the majority of activities
- A needs assessment was conducted
- Friendships forged and support provided
- Improvement of Social Skills
- Increased Communication
- Increased Confidence
- Increased Self Esteem and self worth
- Life skills and qualifications

Successful Outcomes

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- Prevents rural isolation
- Gives opportunity to have a variety of different opportunities
- Promotes happiness/enjoyment
- Improves health and wellbeing
- Helps meets emotional and social needs
- Provides interests and stimulation
- Helps improve verbal ability
- Maintains and increases alertness
- Decrease of anxiety

Conclusion

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- It relies on young people's voluntary participation and commitment.
- It is concerned with both the personal and social development of young people.
- It can involve a wide range of activities and programmes but in the case of any or all of these, from a youth work point of view, the 'process' is as important as the 'product'.
- It has a commitment to uphold core values such as equity, diversity and interdependence; inclusiveness; respect; partnership; empowerment & the safeguarding of young people.
- We try to be socially inclusive, young people can participate in and benefit from it; and it takes special care to support those who have experienced social exclusion.



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Sonas Youth Club
iCARE Centre
Ballymacarry
Buncrana
County Donegal

Eamonn McCarron, Owen Coyle, Erica Curran, Project Sparks, The Liberty Consortium

Playtrail: Training and autism spectrum conditions in schools

Project Sparks is an innovative programme in which young adults with autism spectrum conditions are trained as Leaders to teach music workshops within mainstream primary schools. The project was introduced by one such young leader, Owen Coyle, who spoke about his early experience of struggle in life, and how this has been harnessed in a positive way in order to teach pupils. The project is on course to reaching its target of teaching 680 pupils. Owen talked openly about how he and his fellow leaders have had to fail and get back up again in order to reach their goals. "Every setback has made us stronger and better teachers".

Eamonn McCarron then outlined the rationale and development of the Sparks project in more detail. The project aim is to enable gifted young people with autism to teach music to primary age pupils living in areas of disadvantage. The experience and resilience of the young teachers has been key to their meaningful interaction with pupils.



A video was shown which illustrated how the young leaders use their personal experiences and resilience to teach music and inspire pupils. Eamonn highlighted that the anticipation of being a teacher was a motivating factor for the trainees. At the same time, the project has been careful to provide pastoral care to trainees to address any anxieties which may be created by the task.

In describing the training programme, Eamonn noted the need for a process of differentiation to ensure that training is relevant to all trainees. The course is also very time intensive, and the approach of learning to teach is integrative. The conceptual framework with the programme design isolates each skill involved in teaching and the trainees need to reach fixed levels for each of these isolated skills.

The skills are ranked in a hierarchy as follows:

- **Resilience**
- **Charisma**
- **Making connections**
- **Correcting mistakes**
- **Feedback**
- **Listening skills**
- **Structure**



This approach to upskilling gives trainee leaders 'a focus outside of themselves', and the shared mantra is 'Leader looks different for everyone'. Eamonn concluded that evaluation data has been extremely positive, not only in terms of the social impact on young leaders, but also in providing evidence that the programme has promoted a significantly more affirmative perspective of disability among school children.

Erica Curran summarised the challenges within the project, as follows:

1. **Inhibited meta cognition** – which means it is important to differentiate the approach used for each young trainee
2. **Exposure to failure** – the young leaders are deliberately challenged and are given time and support to fail. Ultimately they need to believe in their ability
3. **Persistence** – each young leader has had to face their fears. She noted that the programme is not suited to all young people with autism spectrum conditions, as it requires going out of personal comfort zones and coping with challenge
4. **Adapting their role** – there is a weekly reflection of progress with the young leaders, with a shared appreciation of the value that 'Leader looks different'
5. **Dismantling limiting beliefs** – the training process requires young people to 'dismantle their own chains' and to free themselves from limiting self-perceptions

Erica reiterated the transformative impact of the project, wherein the leaders transform both themselves and the pupils whom they teach. In closing, a video was shown of a young leader who had successfully trained with Project Sparks, and highlighted how he had drawn from his own negative experiences of school as a way to empathise with pupils.

WORKSHOPS

During the afternoon conference delegates attended their chosen workshops. These interactive sessions comprised two key presentations, along with the opportunity for lively discussion, participation and a sharing of experiences and expertise.

Mental health and wellbeing

Chair: Mark Hammond

Presenters: Jim Weir, EA youth service 'Using a social inclusion model to provide support for mental health'

Targeted Practice Programmes and Autism Spectrum Conditions

Chair: Joe Hawkins

Presenters: Gavin Melly, Playtrail 'Promoting inclusive youth work practice – engaging with young people'

Project Sparks, Playtrail 'Training in schools'

Targeted Practice Programmes and Autism Spectrum Conditions

Chair: Leighann McConville

Presenters: Kati Kiiver, Kao Center Tallinn 'Social stories: supporting coping and social skills'

Connor McGilloway, Youth Action NI 'Empowering young people: Flying the kite for youth participation'

Inclusion, Participation and Community Youth Work practice

Chair: Daryl Moore

Presenters: Gillian Boyd, Youth Matters Cedar Foundation 'Inclusive youth work practice'

Eeva Sinisalo-Juhan, Finland 'Human rights education in youth work – taking account of the rights of diverse young people'

Formal/informal education and school based programmes

Chair: Gavin Deeny

Presenters: Doreen Friel, Crana College 'School Based youth work and ASC'

Elaine Lavery, Youth Action NI 'Sensory programmes – sensory tolerances, social interaction, communication skills and self-regulation skills'

Inclusion, Participation and Community Youth Work practice

Chair: Mark McFeeters

Presenters: Kevin Hughes, YMCA Lisburn. 'Youth work programmes for young people with ASC - A working example.'

Una McCartney, EA youth service 'Inclusive youth work and ASC'



CONFERENCE MANIFESTO

Having listened to the keynote speakers and participated in interactive workshops, conference participants were asked to spend some time at the end of the workshops to develop key recommendations for a conference manifesto, which are presented below. Core recommendations from the speakers have been added to the manifesto where appropriate.

Policy

We should consider disability inclusion more broadly, acknowledging the social model of disability and the rights-based requirements to involve and accommodate people with disability in all aspects of community life.

This type of work needs significantly more resources due to its concentrated nature, slowness of pace and the labour intensiveness (with small groups and individual work). Funding allocation and resources should be distributed on an equitable basis to support the intensity of this type of youth work.

Waiting lists for the assessment of young people with autism spectrum conditions, mental health, and learning disability/additional learning needs must be addressed. With over 2000 young people currently on waiting lists, the knock-on effect in terms of access to support services is potentially life limiting and only exacerbates the sense of crisis.

More research is needed to support young women with autism, as there are disproportionately fewer females being diagnosed than males.

The development of strong partnerships across sectors is essential, and this should also include the provision of holistic services for 18+ year olds.

There should be a universal design for learning, reflecting the view that education is focused 'on the all' and not the few, and that learning is supported in a variety of creative ways.

Youth service policy and programmes which concern diversity need to take a broader focus, eg extending beyond ethnicity and religion to include autism spectrum conditions.

The media should more accurately depict the lived experiences of those with autistic spectrum conditions.

Practice

Our practice must go beyond traditional approaches to strive for opportunities that aim towards optimal well-being. We must challenge the deficit approach, the myth of 'the normal' - the average- in our understanding of inclusion and participation.

Direct engagement with young people is crucial – there is a need for practice to be based on young people's experience and allow young people to take control. Models of participation such as the Lundy model offer guidelines for meaningful participation.

The youth service in its broadest sense should look more holistically in terms of actively reaching out to and engaging the diversity of young people in their communities.

The youth service should adopt the Finnish model which formally links human rights with youth work, in such a way that human rights are interwoven and strategic.

There is a responsibility for everyone to be inclusive.

There should be increased opportunities for practitioners to come together outside of frontline delivery to test out new ideas and methods (where necessary) and refine skills in advance of using them with groups.

There is a need for increased 'normalisation' of inclusive practice – this would look like a more integrated approach to practice.

Where it is possible within budget and staffing confines, youth workers should adopt the proven model of also working closely with the parents of young people with autism spectrum conditions.

As practitioners, we need to think much harder about the youth work environments we create to ensure these are accessible and inclusive for all young people.

Training

Agencies should be mindful of the support needs of staff in this area of work to avoid 'burn-out'. There should be a focus on self-care and self-awareness, supervision, support and staff-wellness.

There is a need for more training in the sensitive area of work in mental health and well-being. Specific and targeted training is needed to equip workers beyond basic care and intervention.

Workers need to be upskilled and have increased awareness of issues surrounding autism spectrum conditions - key pieces of training should enable the worker to deliver a more supportive role.

The training of young people should also be a matter of priority. This would enable them to support their peers with autism spectrum conditions in everyday settings.

CLOSING COMMENTS



In closing the conference Dr. Martin McMullan recapped some of the key messages and ideas which had been expressed over the course of the event. Reflecting on Dylan's comment that 'Inclusion is belonging, inclusion begins with you' he observed how this view aligned with the principles of the strengths-based and rights-based approaches. Martin highlighted how the meanings which young speakers had ascribed to 'inclusion' centred around a sense of belonging, being connected and feeling valued.

The conference had also pointed to the need for further research which would broaden our understanding of the needs of young people. We should listen to them, be led by them, and also open up the conversation with all young people.

Martin proposed that the notion of being 'oppositional' could be put into practice, in that we need to reject traditional ways of thinking, to disrupt the system and to try new things. There is also a need to ensure that the media is given counter-narratives to change their current depiction of autism

He noted that the conference is part of a longer-term commitment by those within the Erasmus+ e-learning partnership. As well as promoting the conference manifesto, the partnership intends to create online digital materials which will support youth work learning.

Finally, Martin thanked a number of organisations and individuals for supporting the conference, including the Erasmus+ funders and partners, the keynote speakers, the workshop presenters and Chairs, the University of Ulster for hosting the event, the catering and physical resources, the administration by the faculty office, Liam Friel and Seana O'Kane, and to Dr Breda Friel for co-ordinating the event. Finally he thanked all those who had attended and contributed so positively throughout the conference.

EVALUATION

As an alternative to a tick box exercise, conference participants were invited to give written feedback to four questions about the conference. Altogether 47 participants submitted comments – without exception these proved to be overwhelmingly positive about the format, content and organisation of the event.

What is one thing that you have learned?

Responses can be grouped around four key learning areas

1. Greater understanding of theoretical perspectives, such as the social model of disability and the need to change society rather than the person, the strengths-based approach, 'new thinking from different cultures', Dabrowski's theory of positive disintegration, the concept of neurodiversity. Responses also included a greater understanding of the importance of language and terminology relating to autism spectrum conditions and disability.
2. Skills and knowledge to change my own practice: responses included the intention to apply the strengths based approach to their own practice, an acknowledgement of the importance of self-care as a practitioner, strategies to turn the negative into positive, a resolution to assess one's own practice and environment, and greater acknowledgement of the importance of responding to the specific needs of the individual
3. An increased understanding of autism, including the complexity of the condition, the impact which social barriers can have on young people, the importance attached to a sense of belonging, to avoid underestimating young people with autism spectrum conditions, realising they can thrive and are talented, and the need to avoid interpreting behaviours as negative
4. Greater recognition of the importance of participation, working in partnership with young people, the value of co-production, the need to listen and work with.

In addition, many participants expressed surprise at the range of 'amazing and innovative inclusion work' which is currently going on, said that they had found the event uplifting, positive and rejuvenating, and in particular they highlighted the inspirational and powerful inputs made by all of the young speakers.

What is something that you will take away and implement/change in the way you work with young people?

There was a variety of responses to this, with many participants resolving to reflect on their own workplace and to apply new strategies within their practice. Responses included;

- Will assess our environment – reflect on own practice
- Apply new skills, and take more of a strengths-based approach
- Make use of new partnerships / explore opportunities for cross border co-operation
- Change my use of language
- Look at opportunities for training (including for young people)
- Develop greater participation – my work will be more young person-led in future
- Target the wider population
- Support young people's transitions

What was something that was missing and/or you wanted to hear more about?

Around half of the respondents said that the event had been comprehensive and they would not have added to it. The majority of those who wanted to hear more referred to practice, including tangible strategies, tools for practice, types of programmes and activities, practical steps to take, more practical skills and advice, more detail about strategies for inclusive youth work, how mainstream youth groups can engage better with young people with autism, and how to work to ensure the general population of young people are more accepting.

Other aspects which participants want to hear more about include mental health training in youth work, young women and masking, more information about the diversity of autism, literature and resources, a list of agencies for referral purposes, the assessment of young children, and more information about the range of learning disabilities.

How would you like to be involved in the future?

The overwhelming response to this was 'another conference' 'more events like this' and more opportunities to learn, share and network. Many respondents expressed their gratitude to the conference organisers and contributors, for example:

The conference was a fantastic way to raise awareness within the youth community. Thanks for having me, it was excellent!

Fantastic day, would love to attend more practical days, learning from practitioners

Found it SO SO informative!

Another conference – this one has been fantastic!

What better way to learn about autism than to hear it straight from the mouths of young people who have a diagnosis of ASC. They are the experts of their own lives, so it is important to hear from them, what it means to them. Not what we think it means to them. Well done to the young people who spoke during the conference today. Inspiring!



CONFERENCE PROGRAMME

Community Youth Work Practice and Autism Spectrum Conditions: **Understanding, Inclusion and Participation**

Friday 25th January 2019. University of Ulster, Magee Campus, The Great Hall

9.00am	Registration and Coffee
9.40am	Welcome to Magee - Philip Mc Dermott, Senior Lecturer, Sociology
9.50am	Opening of Conference – Susannah McCall, Associate Head of School, Applied Social and Policy Sciences
10.00am	Jane Hickey, Victoria University, Melbourne, Australia. <i>Considering autism using a strengths-based approach</i>
10.40am	Breda Friel: <i>Overwhelmed: Living in an intense world</i>
11.10am	Coffee
11.30am	Liam Gill, Darragh Fullerton, Dylan Clark: SONAS Youth Club, iCare, Co Donegal: <i>Promoting positive outcomes with individuals with autism spectrum conditions</i>
12.10pm	Eamonn McCarron, Owen Coyle, Erica Curran, Project Sparks, The Liberty Consortium: <i>Playtrail: Training and autism spectrum conditions in schools</i>
2.00pm	Workshops: Themes and Facilitators and Emerging Manifesto. Workshop presentations consider a range of topics/themes and offer an opportunity to share best practice in CYW practice and ASC.
3.30pm	Plenary
3.50pm	Martin McMullan, YouthAction NI: Closing comments and Thanks
4.00pm	Conference closes



PARTICIPANTS

Community Youth Work Conference Attendees

Name	Organisation
Aidan Carville	Belfast Met & Start 360 - Futures Peace IV Project
Aisling McGrory	HSE, Buncrana
Alex Maters	Belfast Met & Start 360 - Futures Peace IV Project
Andrea McFeely	HSE, School Age Service
Angela Tourish	Inishowen Children's Autism Related Education Limited
Ann Marie Banks	HSE, Sligo
Anne Marie Donnelly	Liberty Consortium
Anne Sharkey	Autism Services, HSE
Aoibhin McNeill	Youth Link NI
Arlene Gill	ICARE
Ayla Friel	Donegal Community Inclusion Training Services
Billy Wilson	Start360
Breda Friel	Ulster University
Breda Rodden	Youthreach, Buncrana
Brendan Hone	Donegal Community Inclusion Training Services
Brogan Wakeley	The Third Space, Verbal
Caoimhe Hegarty	The Third Space, Verbal
Caoimhe Mahony	Youth Link NI
Cara O Kane	YEHA Project
Carmel Burke	Autism Services, HSE
Carmel Kernahan	Start360
Caroline Karayiannis	EA Youth Service
Cassie Campbell	Belfast Met & Start 360 - Futures Peace IV Project
Catherine McGinley	Extern
Catherine O'Donnell	St Mary's Youth Club
Charlotte Cruthers	Belfast Met & Start 360 - Futures Peace IV Project
Chelsie Sparks	YMCA Ireland
Chris Clague	Youth Link NI
Chris Hughes	Belfast Met & Start 360 - Futures Peace IV Project
Ciara McAlinden	Start360
Ciara McKeever	Londonderry YMCA
Claire Morgan	YMCA Newcastle
Conaire Devlin	Belfast Met & Start 360 - Futures Peace IV Project
Conan Robb	EA, Pilots Row Youth & Community Centre
Conchur McCartney	ON Street CY
Connor Brown	St Mary's Youth Club
Connor McGilloway	Youth Action Northern Ireland
Connor Murphy	EA Youth Service
Cormac O'Neill	Northern Ireland Youth Forum
Danielle Doherty	YES NI
Danny Bryce	Children's Services, Extern
Darragh Fullerton	ICARE
Daryl Moore	POBAL, YouthPact
David Gibney	Newstart Education Centre
Dean Larkin	Donegal Community Inclusion Training Services
Dearbhla Holohan	Include Youth
Declan Gallagher	EA NI
Deidre McGee	Autism Services, HSE
Denis O'Neill	Education Authority
Denise Malone	YMCA Newcastle
Derek Cox	UU Certificate in Youth Studies
Doreen Friel	workshop

Dylan Clark	SONAS
Eamonn McCarron	Sparks
Edel Saunders	Peace Bytes
Eeva Sinisal Juva	workshop
Eithne Daly	The Cedar Foundation
Elaine Fallon	Crana College
Elaine Lavery	Youth Action Northern Ireland
Elizabeth McArdle	Ulster University, YouthPact
Emira Quigley-Kane	Youthreach, Buncrana
Emma Jonston	Youth Action Northern Ireland
Erica Curran	Sparks
Erin Moran	Caw Youth Centre
Evelyn McBride	Donegal Community Inclusion Training Services
Gavin Deeney	EA Youth Service
Gavin Melly	Liberty Consortium
Gerard Meehan	YEHA Project
Gillian Boyd	Cedar Foundation
Gillian McClay	YMCA Ireland
Glen Millar	Mencap
Gordon Woolsey	Youth Link NI
Graham Warke	Youth Link NI
Hannah Cammack	The Bytes Project
Hollie Miller	Caw Youth Centre
Ilona Evelyn Rannala	workshop
Jane Hickey	Speaker
Jayne O'Donnell	Youthreach, Buncrana
Jim Peacock	Cedar Foundation
Jim Weir	EA Youth Service
Joanne Donaghy	Youthreach, Buncrana
Joanne Rafferty	Tusla
Joe Hawkins	National Youth Council of Ireland, YouthPact
Joe Nelis	HSE, Buncrana
Karen Conlon	UU Certificate in Youth Studies
Kathleen McHugh	The Forge Family Resource Centre CRG, Donegal
Kati Kiiver	workshop
Katy Broadhurst	YMCA Ireland
Kellie McBride	Donegal Community Inclusion Training Services
Kelly Connolly	Ulster University
Kerrie Gray	Caw Youth Centre
Kerrie McBride	HSE
Kevin Hughes	Lisburn YMCA
Kevin McKenna	Newstart Education Centre
Lauren Stothers	Youth Link NI
Leanne Harte	Include Youth
Leighann McConville	Ulster University, YouthPact
Levi Mann	Street Beat
Liam Gill	Speaker
Lisa Carnduff	Ashton Centre
Lisa Hinds	RISE NI
Lucy Smith	Western Trust
Lynda Conway	Include Youth
Lyndsey Kelly	Extern
Mairead McLaughlin	Spraoi agus Spórt Family Centre Limited
Marianna Cunningham	Autism Services, HSE
Mark Hammond	Ulster University
Mark McFeeters	UU

Martin Dunne	St Mary's Youth Club
Martin McMullan	Youth Action Northern Ireland
Martin Smith	UU Certificate in Youth Studies
Martina Doyle	The Forge Family Resource Centre CRG, Donegal
Matthew McGinley	UU
Meadhbh Dunne	Youth Initiatives
Michelle Curran	Autism Services, HSE
Michelle Reid	Caw Youth Centre
Mikhaila Woods	Mencap
Natalia McGonagle	ASD
Natasha Franklin	Start360
Niall Blee	Include Youth
Nicola McKinney	YEHA Project
Noeleen McGrath	Third Space, The Verbal
Paddy Boyd	Youth Action NI
Paddy Maguire	YMCA Derry
Patrick Doherty	Donegal Community Inclusion Training Services
Patrick Norwood	Street Beat
Pearse McCaffrey	NI Youth Forum
Peter McCann	Ashton Centre
Peter Smith	Cedar Foundation
Philip McDermott	Ywelp/Ulster University
Piarais McCaffery	Northern Ireland Youth Forum
Rachel Leontis	Donegal Community Inclusion Training Services
Robert Lee	YMCA Carrick/Larne
Rory McCarron	The Third Space, Verbal
Sarah McGennity	Mencap
Sari Hoyla	Humak University Helsinki
Sean Devlin	YEHA Project
Sean McNally	Mencap
Sean O'Baoill	YMCA Newcastle
Sharon Dickson	Lisburn YMCA
Shaun McCormick	EA Youth Service
Shauna Hoey	Foroige
Shirley Donegan	TU, Dublin
Susannah McCall	SASS Ulster University
Timothy Crean	YMCA Ireland
Tony Crowe	Belfast Met & Start 360 - Futures Peace IV Project
Una McCartney	Pilot's Row Youth and Community Centre
Vicky McGookin	YMCA Ireland
Yvonne Kelly	Autism Services, HSE

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